Adolescents living with HIV: Checking unhelpful terminology

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ALHIV: Adolescents living with HIV

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Implications and Contribution

Global efforts and challenges in addressing the burden of adolescent HIV have demonstrated language matters. Presently, progress is hindered by the unhelpful and influential use of outdated, inadvertently stigmatising terminology. We propose universal adoption of the terms 'recently acquired HIV' rather than 'behaviourally-acquired,' and 'treatment switch' rather than 'treatment failure.'

The powerful role of language in determining the ways in which we as a society think, feel and act towards young people is sharply evident in clinical endeavours to address the global burden of adolescent HIV. Just as the terminology used to present information in relation to adolescence may 'frame' societal perceptions of this time period as being imbued with either risk or opportunity (1), the language used to describe adolescents living with HIV (ALHIV) must not be erroneously accepted as neutral or harmless. Presently, progress is hindered by the unhelpful and influential use of outdated terminology. Through extensive international qualitative research, we have found that common phrases and labels are inadvertently being used by those designing and delivering healthcare with emotive and negative effects for young people (2). Specifically, we argue the terms 'behaviourally-acquired' (as distinct from 'perinatally-acquired') in relation to mechanism of infection, and 'treatment failure' in relation to progression to second-line antiretroviral therapy are stigmatizing in nature and may undermine engagement in care. At best, such terminology fails to acknowledge and address the complex, intersecting socioeconomic vulnerabilities which contribute to HIV acquisition and compromise treatment engagement during adolescence, especially in resource-stretched settings (3); and at worst, exacerbates these vulnerabilities. Through the lens of adolescent HIV – a complex chronic illness – we illustrate the importance of responding to contemporaneous calls to engage with the core work of re-framing adolescence, and broader cultural and societal changes necessary to better support young people (1).

Replace 'Behaviourally-acquired' with 'Adolescents with recently acquired HIV'

In both the academic literature and in clinical practice, a distinction is routinely drawn between ALHIV based on mechanism of HIV-infection. This practice may have arisen to acknowledge the biomedical differences present in those with long-standing disease (4, 5). There is some

pertinence in characterizing the recency of HIV acquisition and diagnosis, however, the terms 'perinatally' or 'behaviourally' are inadequate to convey clinical circumstance or illuminate individual needs. This binary distinction instead conceals heterogeneity among ALHIV and reveals insufficient engagement with the social consequences of prejudicial language in the epidemic.

Reflective of the intersecting stigma which can characterise HIV and 'adolescents', healthcare workers who judge, scold or sanction young people whom they presume to have acquired HIV through sexual contact or substance use can undermine efforts to support sustained engagement in HIV-testing, treatment and care (6). The term 'behaviourally-acquired', which is rarely if ever applied to adults, is imbued with a sense of individual culpability in relation to risk-exposure. It fails to acknowledge the fundamental role of context in determining individual risk, to which innumerable socio-economic determinants contribute; an evidenced nexus of inequalities of power, gender, age and poverty (2, 3).

Additionally, unhelpful and inaccurate assumptions regarding adolescent sexual activity are perpetuated through the misleading binary created through these terms. We have observed how perinatally-infected adolescents may be infantilized when retained in paediatric settings for inappropriately long periods, with clinicians and caregivers reluctant to broach sexual and reproductive health discussions (7). Conversely, those who acquired HIV during adolescence may be allocated inappropriately early to adult clinics with limited experience in managing the psycho-social needs of adolescence (8). In both situations, disadvantage results from assumptions linked to use of these labels, as ALHIV are not provided with developmentally-appropriate information to support their transition towards adulthood.

ALHIV experience one clinical condition, heavily imbued with social complexities, physical sequelae and psychological challenges (5, 9). Specific considerations should be attributed to individual context and recency of diagnosis. The importance of sensitive, tailored care is paramount (8, 9). Adopting the terms 'recently acquired HIV,' 'acquired during adolescence,' and 'vertically acquired' represents a deliberate shift in emphasis and are more indicative of individual support needs, priorities and contextual factors.

Replace 'Treatment failure' with 'Treatment switch'

Similarly, the term 'treatment failure' is frequently used to describe the transition to second-line antiretroviral therapy. We propose the use of the more neutral term 'switch'. Qualitative research conducted among ALHIV indicates application of the term 'treatment failure' may be interpreted quite differently by adolescents in comparison to the intention of healthcare workers. For example, when young people are switched to second-line treatment they may be described as having 'failed treatment,' or are framed as being 'treatment failures'. Switching treatment regimens is therefore characterized by fear and blame (10); impeding candid disclosure by adolescents in relation to their adherence behaviour, and precluding therapeutic discussions between adolescents, caregivers and clinicians to resolve adherence challenges.

In practice, adherence behaviour does not occur in isolation, and the notion of 'treatment failure' is not reflective of the complex social and structural conditions which undermine adherence (10). Further, rapid shifts from caregiver-mediated to autonomous treatment-taking appear to often precipitate deteriorations in adherence behaviour, suggesting relational support is being withdrawn too quickly for young people to effectively adapt (10). As such, adherence is situated within a tight knot of concerns in a young person's life. Throughout the adolescent

period, ALHIV encounter multiple changes in their circumstances and responsibilities. Adherence behaviour is not static; fluctuating treatment engagement should be anticipated. Clinical discussions should focus on relationally-orientated solutions which involve significant others in the provision of a supportive scaffold around the young person; developing competency, social support and self-esteem as mechanisms to enhance adherence. The term 'switch' better reflects the dynamic changes needed in caring for ALHIV.

Conclusions

Global efforts and challenges in addressing the burden of adolescent HIV have demonstrated that language matters. We must be thoughtful in the terminology we utilise in the academic literature, research and, especially, in practice because it influences how adolescents affected by a particular clinical condition are framed. We need to deliberately shift towards terminology which is not inadvertently judgmental or accusatory in nature. Adopting more just language can be an integral part of our response to improving engagement and care for ALHIV across the world by opening up opportunities for change, fostering supportive clinical environments and leading the way for social change.

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